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# 'And then you can decide' – antenatal foetal diagnosis decision making in South Africa

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## Abstract

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**Background** Decision making is integral to genetic counselling and the premise is that autonomous decisions emerge if patients are provided with information in a non-directive manner. The pivotal activity in antenatal diagnosis counselling with at-risk pregnant women is decision making regarding invasive procedures. This process is not well understood in multicultural settings.

**Objective** This study examined multicultural genetic counselling interactions with women of advanced maternal age (AMA). It aimed to investigate the participants' orientation towards the amniocentesis decision.

**Design** Data were collected during 14 video-recorded consultations between six genetic counsellors and 14 women of AMA in a genetic counselling clinic in South Africa. The design was qualitative and conversation analysis was used for analysis.

**Results** Analysis revealed that counsellors used several strategies to facilitate discussions and decision making. However, the invitation to make a decision regarding amniocentesis was not perceived as being neutral. Both the counsellors and the women appeared to treat the offer as one which should be accepted. This resulted in a paradox, as strategies intended to allow neutral discussion seem to achieve the opposite. It is suggested that these results may be linked to the local health-care setting.

**Conclusion** The results suggest that the understanding of decision-making processes and enhancing autonomy may require a more detailed investigation into psychosocial, political and historical factors in the local health-care setting. Models of practice as well as the training of genetic counsellors need to be sensitive to these influences. A closer examination of interactional variables may yield new and relevant insights for the profession.

## Introduction

In genetic counselling, the genetic counsellor's role is to provide information about the relevant genetic conditions, risks and testing options so that women or couples can make informed decisions.<sup>1–3</sup> A non-directive approach is advocated with the premise that the information given should be unbiased and neutral and that the counsellor should not influence or advise on a specific course of action.<sup>4,5</sup> This approach is believed to enhance patient autonomy and result in informed decision making.<sup>5–7</sup> A non-directive approach aligns with patient-centred communication as both emphasize care that is attuned to patients' needs, values and preferences.<sup>8</sup>

Research on antenatal genetic diagnosis counselling has highlighted the difficulties in understanding, maintaining and measuring non-directiveness (ND),<sup>9–14</sup> particularly in clinical practice where approaches vary in different circumstances.<sup>11,15–19</sup> One of the problems is that there is no agreed upon definition for ND in the profession.<sup>4,5,20,21</sup> Studies based on interviews with health-care providers and studies on counsellor–patient interactions have been perceived as conflicting. Some findings on actual interactions have shown that genetic counsellors may practice directly.<sup>11,22</sup> In the linguistic literature, however, it was found that the ideal of ND is not attainable in an interaction as whatever health professionals do may influence the interaction. It is therefore possible that genetic counselling studies based on interaction data may reflect the fact that no interaction can be truly non-directive. Further insights concerning the impossibility of attaining the ideal of ND are from Clarke<sup>23</sup> and Weil<sup>24</sup> who state that merely making an offer of amniocentesis testing suggests that it should be accepted.

Further, what has been difficult to assess is how informed decision making can be achieved and patient autonomy maintained. Interactional research is limited on this topic, and it is uncertain if ND enhances patient autonomy. Marteau *et al.*'s<sup>2</sup> definition of informed choice, 'an

informed choice is one that is based on relevant knowledge, consistent with the decision-Maker's values and behaviourally implemented', can be criticized as being too narrow.<sup>6</sup> It suggests that decision making is an isolated process which takes place on an intellectual level. The influence of professional bias, commercially driven health-care supply, interactional contingencies and other contextual influences were not taken into account in this definition.

Little is known about the factors which influence decision making in intercultural clinical settings. Decision making in genetic counselling interactions has been shown to depend on setting, context<sup>13,19</sup> and social structures, including cultural values and beliefs. These factors are thought to influence the provision of genetic counselling services in relation to prenatal diagnosis and termination of pregnancy.<sup>23,24</sup> The genetic counselling interactions in this study are largely multicultural, and patients are required to communicate in their second or sometimes third language. An investigation of counselling practices in the genetics clinics is thought to aid in our understanding of the nature of service delivery and uptake. While interactional research may not answer all the questions, it is a resource that has been underutilized. Such research can make a significant contribution to the understanding of counselling practice, and how theories are operationalized in actual interactions.

South Africa is a country with much linguistic and cultural diversity; 11 official languages and various religions are practised (e.g. Christianity, Judaism, Hindu, Moslem, Baha'i). Many disparities in access to health care continue to exist, and South Africa has a significant disease burden due to HIV/AIDS.<sup>25,26</sup> In addition, many patients make use of traditional healers and their medicines.<sup>27</sup> Genetic counselling services were first offered in the 1970's and are available at several sites in the state/public sector.<sup>28–31</sup> Limited services are available in the private (individually funded) sector. The country had 11 practicing clinical geneticists and 10 practicing Masters trained genetic

counsellors in 2013.<sup>31</sup> Models of genetic counselling training have been Western based, drawing on principles of Kessler's counselling practice model.<sup>32</sup>

This study, conducted within the unique cultural context of South Africa, examined the decision-making phase of the genetic counselling sessions with women of AMA. These women are at an increased risk of having a baby with a chromosome abnormality, such as Trisomy 21, 13 and 18. The women are counselled about their risks and testing options and an amniocentesis, which is performed in the second trimester, is offered as the foetal cells sampling procedure for chromosome analysis. This research results from efforts to understand the genetic counselling interactions in the local multicultural context. The objective of this paper was to investigate how women are invited to make a decision, regarding having an amniocentesis performed, while meeting with a genetic counsellor. An 'invitation' refers to a discussion about the procedure and the possible outcomes. This paper argues that this invitation is perceived as an offer which both the counsellors and the women treat as an offer with a preference for acceptance.

## Methods

### Participants

In total, 14 genetic counselling sessions were recorded. The 14 women were between 35 and 43 years of age, and their first language was one of the South African indigenous languages (Sesotho, IsiZulu, Setswana, IsiXhosa or Afrikaans) except for one woman, from the Democratic Republic of Congo, whose first language was Ibo. Six genetic counsellors conducted the sessions (two to four sessions each); their age ranged from 27 to 51 years, and their first language was English.

The 14 sessions were with women of advanced maternal age who attended a genetic counselling consultation conducted by a Master's trained registered genetic counsellor in one of the state-funded hospitals in Johannesburg. In these

settings, advanced maternal age (AMA) was defined as being at or over the age of 35 years. The women were in their second trimester of pregnancy and were referred to the genetics clinics by sonographers, nursing staff, obstetricians or foetal medicine specialists. The women were recruited during their genetic counselling clinic appointment and attended the session alone, with the exception of one woman who was accompanied by her partner. Although the clinic was based on pre-bookings, the number of women who attended on a specific day varied. Due to logistical constraints, only one session per day was recorded. The patient participants were considered a vulnerable group as they received a service and could have felt compelled to give consent. Being mindful of this potential vulnerability, the recruitment for the study was mediated by a culturally matched research assistant. It is hoped that this helped minimize coercion, but it is acknowledged that the setting, because of its medicalized context, is inherently asymmetrical.

The data consisted of video-recorded genetic counselling interactions (45–60 min) between the genetic counsellors and the women. All 14 sessions were conducted in English. During the genetic counselling sessions, the counsellors and women talked about the genetic risk, the amniocentesis procedure, the procedure related abortion risk, having a baby with abnormalities and having an abnormal test result. This information giving process culminated in the counsellor inviting the women to make a decision.

Relevant ethical clearance was obtained via the University of the Witwatersrand Research Ethics committee (Ethics clearance number M070222).

The first author continued to practise as a genetic counsellor throughout the project and was constantly aware of the effect the two activities, the practising of and analysing the practice of genetic counselling, had on each other. Self-reflection occurred throughout the research. Keeping notes, engaging in discussions with the research supervisor, mentor and other colleagues provided opportunities for

challenging ideas. In addition, valuable comments were received when presenting the data that further challenged and shaped research ideas. It is however acknowledged that at some level, bias would continue to be present.

### Data collection and analysis

The genetic counselling sessions were video-recorded, transcribed using transcription conventions by Jefferson<sup>33</sup> and (see appendix) analysed using qualitative approaches. The sessions were examined using principles of conversation analysis (CA).<sup>34,35</sup> CA, as a method for analysing interactions, is based on the observation that participants in interaction can only communicate through what they make observable for each other.<sup>34,35</sup> They have no direct access to the other's intentions or interpretations and are only able to communicate successfully by displaying to each other how they want to be understood (in the ways they design their utterances) and how they understand the other (in the ways they respond). The aim was to investigate the practices by which participants achieve common, intersubjective understandings and how actions are organized in sequences, such as questions and answers, and offers and their acceptance/rejection. The analysis focused on describing how the decision of undergoing an amniocentesis is negotiated between the counsellor and the woman.

## Results

The genetic counselling sessions in this setting were found to have a clearly discernable structure and six phases could be identified. These were defined as: an opening, information gathering, information giving, a decision-making,

counselling and closing phase. The pivotal activity of the counselling session was that the woman was invited to decide whether or not she wanted to have an amniocentesis performed in order to provide a foetal sample for chromosome analysis. These discussions took place during the decision-making phase. During the discussions, the counsellors referred to the amniocentesis sampling procedure as the 'amniocentesis test'. The focus of this article is on the decision-making phase in which the counsellor and the woman engaged in a discussion about whether or not an amniocentesis should be performed. It is during these discussions that amniocentesis is offered. In most cases, the decision regarding amniocentesis was not made instantly but rather developed during the course of the discussions. It was found that the counsellors guided the women through the process by engaging them in several aspects of the decision. This was done by inviting the women to think about the risks (the risk of having a child with a chromosome abnormality and the procedure related spontaneous abortion risk), the outcomes of having testing or not testing and having either an affected or unaffected child.

The counsellors were found to make use of several strategies to engage the women and facilitate the decision-making process. These strategies included perspective display questions (PDQ) which were designed in such a way that they invited the women to adopt introspection so that they could share their feelings and thoughts.<sup>36</sup> Excerpt one is an example. In all the excerpts, C is the counsellor, W is the woman, P is the partner and pseudonyms are used to protect confidentiality. The transcription conventions can be found in the appendix.

### (1) Session 01, Couns C – PDQ

→ 1242	C:	(.) how? would <u>you</u> feel if <u>if</u> we did this test and we
1243		picked up your baby had a problem. (.) how would you
1244		feel? what would be(.) <the right thing (.) for <u>you</u> >
1245		(3.0)
1246	W:	no? I'd rather stay with my child it's [fi:ne]

**(2) Session 05, Couns B – If/when questions**


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→1079	<b>C:</b>	Thembi if we didn't if we can't do the test (.) and we
1080		found that and the baby is born (.)if the baby did
1081		have a problem (.) how do you think that would be for
1082		you
1083		(3.0)
1084	<b>W:</b>	No its going to be hard to know but eish?
1085		(1.0) I must accept

---

Line 1084 'eish' is a local phrase used in different contexts. In this transcript, it signifies despair.

**(3) Session 15, Couns E – Sketching a scenario**


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→1121	<b>C:</b>	so(.)you must <u>think</u> (.)about(.)how you <u>feel</u> (.) <u>because</u>
1122		(.) some people as I say to you they say >we are not
1123		going to do the abortion< but we want to know so we
1124		are>gonna do the test.<
1125	<b>W:</b>	yes
1126	<b>C:</b>	other people say to me(.) we are not gonna do the
1127		abortion. and we <u>don't</u> want this test because of <u>this</u>
1128		chance to make a miscarriage [we don't want]
1129	<b>W:</b>	[ (miscarriage) ]
1130	<b>C:</b>	to take that chance
1131	<b>P:</b>	ja
1132	<b>C:</b>	s:o? different people they feeling? different things.
1133	<b>W:</b>	uhm

---

Line 1131 'ja' Local work meaning 'yes'.

**(4) Session 11, Couns A – Weighing up options**


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→1731	<b>C:</b>	And I <u>suppo:se</u> its saying my chance of having a baby
1732		with a problem?
1733	<b>W:</b>	uhm
1734	<b>C:</b>	is about hun <u>ONE</u> in a hun in two hundred and forty
1735	<b>W:</b>	uhm
→1736	<b>C:</b>	and the chance to have a <u>miscarriage</u> it is? higher than
1737		the chance to have a baby with problems

---

**(5) Session 13, Couns E – Opening statements**


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→74	<b>C:</b>	so I'm gonna (.) tell you > <u>all</u> ? about< those thhes[ts]
75	<b>W:</b>	[ye:s]
→76	<b>C:</b>	and then and then you can dhhecede.
77	<b>W:</b>	°ye:s°

---

The counsellors also used a number of different question formats and what if/when questions to encourage the women to think about a hypothetical future as shown in excerpt two.

Further, the counsellors sketched scenarios for the women by referring to how another patient had dealt with a similar situation (excerpt three).

**(6) Session 01, Couns C – Overt orientation to ND**


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→1242	C:	(.) how? would you feel if <u>if</u> >we did this test
1243		and we picked up your baby had a problem<.
1244		(.) how would you feel?
1245		<what would be (.)the right thing (.) for <u>you</u> >
1246		(3.0)
1247	W:	no? I'd rather stay with my child it's [fine]
1248	C:	[stay with]
1249		your [child]
1250	W:	[Ja]
1249	C:	okay
1250	W:	uhm
1251	C:	so for [you-]
1252	W:	[I'll just] accept
1253	C:	°okay° so for <u>you</u> if your baby has a problem, like this
1254		it would be okay.
1255	W:	ja
1256	C:	you would accept it.
1257	W:	°uhm°
1258	C:	and I know you said earlier it's a gift from [ <u>Go:d</u> ]
1259	W:	[uh:m]
1260	C:	so for <u>you</u> you'd feel it's a gift
1261	W:	uhm
→1262	C:	from God. (.) and it is <u>your</u> choice↓
1263	W:	ja, I
→1264	C:	we're just here >to provide you with the information <
1265	W:	okay
→1266	C:	but it's > <u>completely?</u> up to you as to<
1267	W:	uhm
→1268	C:	>whether or not you <u>want?</u> to have this test<
1269	W:	yes
1279	C:	or not.

---

Further, the counsellors compared two outcomes by 'weighing them up' against each other (excerpt four).

By engaging with the women on all the different aspects involved in deciding whether to have an amniocentesis, the counsellors used active counselling techniques. These techniques have been discussed in the debate about ND and how ND can be achieved in practice.<sup>4,20,21,37</sup> Reflective elements, such as the PDQ questions used by the counsellors, were shown to be markers for non-directive genetic counselling.<sup>15</sup> The counsellors made use of both reflective strategies and recurring questions in this antenatal context in order to adhere to the ethos of ND.

Counsellors introduce the amniocentesis decision as an offer in the openings

The fact that the women were required to make a decision regarding having an amniocentesis performed, was presented early on in the session during the opening phase. The counsellors first described what was going to happen during the session and what the test involved, and they then explained that the women would be required to make a decision regarding antenatal testing. Excerpt five below illustrates such an introduction.

The counsellor, in line 74, states that she will inform the woman about the available tests and goes on, in line 76, to say 'then you can decide'.



**(7) Session 10, Couns C – Overt orientation to ND**


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1302	<b>C:</b>	okay and that's the test I understand (.) you say you
1303		do↑n't want to have.
1304	<b>P:</b>	<sup>0</sup> (I don't want to have it) <sup>0</sup>
→1305	<b>C:</b>	and that's <u>absolutely</u> ↑ your choice (.) we just here to
1306		give you the information
1307	<b>P:</b>	<sup>0</sup> ye:s ye:s <sup>0</sup>
1308	<b>C:</b>	okay

---

With this exchange, the counsellor indicates an order of events in which information giving will be followed by decision making. In line 76, the counsellor states explicitly that this decision is the woman's responsibility.

The outcome of the discussion could result in the woman having an amniocentesis, not having an amniocentesis or deferring the decision. The focus in this article, in keeping with CA principles, is on the sequential organization of the interactions and not on the ultimate outcome of the decision.

#### Differences in the counsellors' uptake of the women's responses

During the discussions, it was found that the counsellors treated the women's responses differently. When the women indicated that they did not want to have an amniocentesis performed, the counsellors showed an overt display of ND, emphasizing that this was the woman's choice. Excerpt six illustrates such a response.

The excerpt starts with a what if/when question challenging the woman to think about a hypothetical future, specifically how she will feel if she has an amniocentesis and a chromosomal abnormality is detected on analysis of the sample (lines 1242–45). The woman states in line 1247 that she will 'stay with my child'. Thereby indicating she is not in favour of having an amniocentesis performed. The overt display of ND is evident when the counsellor states 'it is your choice' (line 1262), and 'we are just here to provide you with the information' (line 1264) and restating again 'but it's completely up to you' (line 1266) and 'whether

or not you want to have the test' (line 1268). The intonation in the counsellor's talk, when she pronounces the words 'completely' and 'want' with stress, further emphasizes and reminds the woman that this is a personal choice. The woman produces corresponding confirmations in lines 1263, 1265, 1267 and 1269.

Similarly in excerpt seven, the same display on ND is evident in line 1305 where the counsellor explicitly states it is the woman's choice. She also emphasizes the word 'absolutely' and goes on to say that her role is to provide information.

This ND display was not found in the counsellor's responses to the women when they indicated that they were interested in having an amniocentesis. Here, the counsellors acknowledged the woman's decision and did not display the same emphasis on it being the woman's own choice, as extract eight illustrates.

**(8) Session 11, Couns A – Acknowledge decision**


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1199	<b>C:</b>	HOW DO how do you feel about all of this (.)
1200		about having? thiste:st?
1201	<b>W:</b>	I want to have a thhest
1202		(1.0)
→1203	<b>C:</b>	[you want to have it]
1204	<b>W:</b>	[so that I must] know [ <u>very early</u> what is]
→1205	<b>C:</b>	[(want to see better)]
1206	<b>W:</b>	going on
→1207	<b>C:</b>	ohhka:y.
1208	<b>W:</b>	uhm
→1209	<b>C:</b>	you want to know
1210	<b>W:</b>	uhm

---

The extract starts with a PDQ inviting reflection.<sup>36</sup> In her response, the woman does not treat it as such, but answers the counsellor's



**(9) Session 13, Couns E – Acknowledge decision**


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1160	<b>P:</b>	so I (.) uh uh(.) >the on↑ly thing I can
1161		tell you<I <u>do</u> need the test>
1162	<b>C:</b>	<sup>o</sup> oka:y <sup>o</sup>
1163	<b>P:</b>	Ye:s is that that is the (.) bigger <u>chance</u> for me to be
1164		relie:ved on my mind you know.
→1165	<b>C:</b>	so you <u>want</u> to have the [information.]
1166	<b>P:</b>	[Yes yes] I [want to]
→1167	<b>C:</b>	[So that]
→1168		you can know

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**(10) Session 01, Couns C – Decision as an expectation**


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1242	<b>C:</b>	(.) how? would <u>you</u> feel if <u>if</u> we did this test and we
1243		picked up your baby had a problem. (.) how would you
1244		feel? what would be(.) <the right thing (.) for <u>you</u> >
→1245		(3.0)
→1246	<b>W:</b>	no? I'd rather stay with my child it's [fi:ne]

---

how-question by indicating that she wants to have an amniocentesis (line 1201). In line 1204 and 1206, the woman treats the counsellor's response as an invitation to reflect as can be seen by the woman giving a reason for wanting to be tested ('so that I must know very early what is going on'). The reflective approach taken by the counsellor (mirroring in lines 1203 and paraphrasing in line 1205) indicates that she has accepted the woman's decision. In turn, the counsellor's further responses (lines 1027 and 1209) are a series of 'checks', first she says 'you want to see better', then she responds with 'okay' and again explicitly states 'you want to know', further indicating an acceptance of the woman's decision.

Another example is shown in excerpt nine, where the counsellor in lines 1165, 1167 and 1168 performs similar 'check' in response to the woman's response that she wants to undergo the procedure.

What emerged in the data, therefore, is that the counsellors' response to the two alternatives is asymmetrical, with the uptake of the women's yes-response (indicating they want testing) being different from their uptake of a no-response (indicating they do not want testing). When the women indicated a positive

decision (an indication that they would want to have the procedure), the counsellors were likely to accept and acknowledge the decision, but when the women indicated a negative decision (an indication that they did not want to have the procedure), the counsellors entered into an overt display emphasizing the women's right and obligation to choose. This suggests that the counsellors showed a preference for a yes-response. This preference suggests that the counsellors' invitation to the women to make a decision regarding the amniocentesis procedure was an offer, requiring acceptance. As CA research has shown, offers embody an inherent preference for acceptance over rejection.<sup>38</sup> In these transcripts, this preference is also evident in the women's responses.

The women treat the information as an invitation that should be accepted

The women's orientation to a preference for a yes response can be seen in the way the women treated the counsellors' questions or invitations, as illustrated in excerpt ten. The woman treated the counsellor's invitation to make a decision as if she was expected to accept the amniocentesis.

**(11) Session P02, Couns B – Decision as an expectation**


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→821	C:	What are you thinking?(1.0) how do you feel about
822		this? (1.0)
→823	P:	Ja: I see but >I mean in< my↑ case since I told you that
824		I stru↑ggled to have babies >I <u>don't</u> want to to take a
825		chance<
826	C:	°Oka:y°
827	P:	Ja
828	C:	>Alright<

---

The counsellor asked three consecutive open-ended questions (1242–445) to invite the woman's decision in the form of PDQ. The woman however did not treat these as an invitation to reflect but rather as a question requiring a 'yes' or a 'no' answer when she answers 'no' (line 1247). Not only is her answer given after a three second pause, but she also produces a reason for her answer. In her response, she explicitly states 'no'; she then says, 'stay with my child' and ends with 'its fine'. A polar question generally has two alternative responses either a 'yes' or a 'no'. The preferred alternative is produced in immediate response to the initiated action, while the dispreferred alternative is produced while distancing the response from the initiative.<sup>38</sup> Such distancing is characterized by inserting items between the initiative and the response such as 'well', phrases such as 'I would have liked to but...', or as in this excerpt, a pause (line 1246). The woman's response thus suggested that she treated the counsellor's invitation as an 'offer' to be accepted, rather than as a question. The woman also added 'it's fine' (line 1246) and thus produced a reason for her answer which further showed her orientation that there was a preference to agree with having the test performed. Even though the counsellor may not have intended her wh-interrogative to imply a preference for agreeing to the test, this woman treated it as such.

Another example is shown in excerpt eleven where again the woman's response shows that she treated the counsellor's invitation as an offer with a preference for acceptance.

In line 823, the woman's response contains a 'but' and ends with stating explicitly that she

does not want to take the risk. As stated above, certain responses, such as 'but' are seen in situations where the person is about to give a response that s/he perceives as dispreferred. This is another example from the data showing the woman's perception that the offer of amniocentesis is an offer that should be accepted.

## Discussion

The analysis of the data has shown that the option of amniocentesis is not perceived as 'neutral'. Both the counsellors and women appeared to perceive the choice of whether to undergo an amniocentesis as an offer which should be accepted. An important observation from the analysis is that this preference is not evident in the counsellor strategies. This preference shows, primarily post-hoc, in the counsellors' different responses to a positive and negative decision and in the way the women respond to the invitation to decide. Thus, as shown in CA research (offers are associated with a preference for acceptance),<sup>38</sup> no matter what the counsellors do they cannot present the option of amniocentesis as neutral. This could be interpreted as the counsellors practicing directivity,<sup>11,22</sup> but the findings from this study rather reflect the notion that no interaction can be truly ND and neutral. The findings also provided some evidence for Weil<sup>23</sup> and Clarke's<sup>24</sup> arguments that the mere offer of amniocentesis suggests that the offer should be accepted, similarly showing that an interaction cannot be neutral.

Simultaneously, the analysis confirms the active role that counsellors play in engaging the women in a discussion regarding their

decision making and highlights the use of different strategies, such as the use of PDQ, scenarios and weighing up options which either overtly or less overtly orientated towards the decision. The transcripts showed the great effort the counsellors took and the active role they played which seemed, both to present the information in an unbiased way and to assist the women to make an autonomous well informed decision. In fact, the counsellors employed textbook advocated ND strategies (open-ended questions, PDQ, what/if questions and formulations).<sup>5,15</sup> Whether these strategies are truly promoting client autonomy<sup>4-6</sup> is not clear. Certainly, the data suggest that the decisions are often challenged, as seen by the use of several of the counsellors' strategies. The extreme care that the counsellor takes in ensuring the woman's understanding of her choices and the impact of her decisions may paradoxically be placing more pressure on the women, some of whom then have to deploy resistance behaviour to demonstrate the firmness of their decision. There seems to be tension between ND and directiveness which shows in the data and which reflects many of the on-going issues faced by genetic counsellors.

A further influence on these sessions is that the women did not seek the service but were integrated into a referral system. This is typical of the South African public health service where patients are referred to services from the various clinics and they have little say in their health-care management. Due to poverty, historical inequity and ignorance, patients often have limited choices in their health-seeking behaviour. Further, in the case of many patients (80%) who seek encounters with traditional healers, these interactions tend to be organized as much more directive and not involving client decision-making.<sup>39</sup> Due to pressure on the health system, these women are probably familiar with more directive forms of medical communication and very short and direct interactions with health-care professionals. Thus, the nature of the genetic counselling session, in its length and its stated function, may come as a surprise, as it contrasts with the

women's previous experiences. In the session, women are invited to make decisions and weigh up choices and, due to the circumstances, often without the support of a partner or family members. In the data from the present study, it can be seen that the women showed their awareness of this different experience and of the unusual invitation to make decisions for themselves. The question of client autonomy in this health-care context thus becomes pivotal. A positive stance on autonomy,<sup>6</sup> born from a desire to appear ND together with a narrow view of autonomy, may not be promoting autonomy. This coupled with the inequity and asymmetry in the health-care context to which most women are accustomed (both in the past and in other current antenatal settings) may have the effect of making their voice (or their perceived voice) weaker in the context of the genetic counselling clinic. Both the counsellors and women seem to be aware of this issue and co-construct a dialogue which may become ambivalent. In this context, the pursuit of a goal, such as informed choice, the essence of client autonomy, may become a contentious issue for genetic counsellors. Far from enhancing autonomy, some of the strategies used may serve to erode autonomy and highlight the asymmetry (between counsellor and client) in the interaction,<sup>40,41</sup> a state which, because of gender and perceptions of the role of the health professional, may already be tenuous and suppressed.

These features are not entirely unique to this context, and there is evidence that some emerge in medical interactions in general<sup>42</sup> and in genetic counselling sessions elsewhere.<sup>13,19</sup> However, language issues, training frameworks, cultural incompatibility and the relative inexperience of the profession in the country are inextricably intertwined with the provision of genetic services.

## Conclusion

In South Africa's multicultural setting, unique challenges are faced in managing the ideals of the profession. The findings of the present

study suggest that decision-making processes and enhancing autonomy may require a more detailed understanding of potential barriers, which link to psychosocial, political and historical factors in the health-care setting. Models of genetic counselling practice and training need to be sensitive to these influences. It is suggested that a closer examination of interactional variables occurring in counselling sessions will help yield relevant dimensions for professional practice. If the goal of the profession is 'helping clients reach a decision wisely, rather than reach a wise decision',<sup>37</sup> then as the findings from this study suggests a closer examination of the linguistic and interactional strategies used to reach such a goal is clearly worthwhile.

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## Supporting Information

Additional Supporting Information may be found in the online version of this article:

**Appendix S1.** Transcription conventions.

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